

BETWEEN TWO WORLDS:  
AN EXPLORATION OF PRIVACY MANAGEMENT ISSUES ARISING FOR FIRST-  
YEAR COLLEGE STUDENTS DEALING WITH A MOTHER'S BREAST CANCER  
DIAGNOSIS AND TREATMENT

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## DEDICATION

To Aron DiBacco, my friend and colleague, in the Communication Graduate Program, whose encouragement and support has enhanced my time at IUPUI.

To my professors in the Communication Graduate Program, who have stretched me beyond what I thought I was capable of and who have taught me so much.

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## INTRODUCTION

One of the more significant periods in the life of a young adult is the transition from high school into college (Fisher & Hood, 1987). This transition to university life from high school often involves many challenges for young adults (Bernier, Larose, & Whipple, 2005). For the young adult, attending college often requires breaking from previous lifestyles and routines, adaptation to new academic and social environments, and increased responsibilities (Fisher & Hood, 1987). The unfamiliarity of university life and the fear of not living up to family or personal expectations contribute to a young adult's adjustment phase upon entry into a university (Blimling & Miltenberger, 1981). As a whole, the first year of college is a transition period that places "adaptive demands" on the young adult (Hudd et al., 2000). Complicating this transition is the possibility of a parent being diagnosed with a life threatening illness such as breast cancer.

Breast cancer is an illness that often has a significant psychological and emotional impact on both the patient and the patient's whole family (Billhult & Segesten, 2003). Those who have been diagnosed with cancer often express their uncertainty of how, what, and how much to disclose to family members about their illness (Barnes, Kroll, Burke, Lee, Jones, & Stein, 2000; Billhult & Segesten, 2003). Many parents who have been diagnosed with breast cancer have expressed their concern over what strategies they should use to communicate about breast cancer with their children (Billhult & Segesten, 2003). Retrospective studies have shown that many parents struggle with whether or not to disclose their life-threatening illness to their children (Barnes et al., 2000). On the other hand, children of breast cancer patients are often aware to some extent about the illness and often experience higher levels of anxiety when parents choose not to disclose

information about the illness to them (Barnes et al., 2000; Billhult & Segesten, 2003). Consequently, communication among family members is identified as a critical factor in the family's adaptation and coping with breast cancer (Billhult & Segesten, 2003). The difficulty families face in communicating about breast cancer can have a strong impact on their emotional and psychological adaptation to this life altering circumstance (Billhult & Segesten, 2003). Also, adult children, including young adult children, must assume the role of caregiver and/or confidant to their parents (Ferrell, 1998; Ferrell, Ferrell, Rhiner, & Grant, 1991). As a result, these adult children experience psychological distress due to the demands of fulfilling multiple roles (Brody, 1981; Mosher & Danoff-Burg, 2005; Shanas, 1979). During the first year of college, the young adult is already faced with multiple demands on their time and social life (Hudd et al., 2000). A diagnosis of parental breast cancer in the family adds another significant stressor for the young adult child. The difficulties that families experience in communicating about breast cancer and the struggles families face in balancing multiple role demands add significant stress to young adults adapting to their first year of college.

### Purpose of Study

The purpose of this study is to examine the way college students, in their first year at school, coped with learning that one of their parents was diagnosed with breast cancer. This study is conducted using a semi-structured interview method of data collection and qualitative analysis. The research focuses on the perspective of the first-year college student. This study assesses how the students believed they learned about the diagnosis; how they felt the diagnosis impacted their ability to deal with the demands of college in

their first-year, and their perceptions of how the parents managed the flow of information to and from their children (first year students) about the illness and during treatment.

### Communication Privacy Management Theory

This study depends on Communication Privacy Management (CPM) theory (1994, 2002, 2006) because it provides a framework for evaluating communication issues about privacy and disclosure that arise in everyday life. Communication privacy management is an evidenced-based theory that is dialectical in nature based on the concept positing that “people make choices about revealing or concealing based on criteria and conditions they perceive to be salient, and that individuals fundamentally believe they have the right to own and regulate access to their private information” (Petronio, 2002, p. 2). The dialectical nature of CPM is beneficial for evaluating how parents choose to reveal or conceal information about their breast cancer to their young adult college students and what young adults choose to do with this information once it is communicated. For a first year student as well as the student’s parents, it is possible that this can be a particularly difficult process.

Given the difficulties in navigating communication about breast cancer, privacy issues may arise for young adults during their first year of college as they seek to establish independence while remaining connected to family (Arnett, 2000; Beck, Taylor, & Robbins, 2003; Fisher & Hood, 1987) and the complexities families face when communicating about maternal breast cancer coupled with adjustments to a new environment at school (Barnes et al., 2000; Edwards et al., 2008; Callan & Noller, 1986). This study explores privacy and disclosure of breast cancer between family members and the young adult attending college for the first time. This research focuses on the young



adult's privacy boundaries and rules that are shaped, created, or broken during their first year of school due to the stresses of the family illness and their college experiences.

## LITERATURE REVIEW

Utilizing Petronio's theory of CPM provides a fitting framework for analyzing the motivations, spoken and unspoken rules, and methods used in revealing or concealing information in each family who has faced breast cancer and the first year of college (Petronio, 2002). According to CPM, each person has privacy boundaries around the information they consider to be their own. In the case of parents who are diagnosed with breast cancer, they may feel a sense of ownership about their breast cancer diagnosis, prognosis, and treatment information. CPM uses the metaphor of a boundary to represent the border around private information that a person or group owns (Petronio, 2002). People feel a sense of ownership for certain information, and they place boundaries around this information. Desiring to respect their young adults' autonomy or to protect their young adults from added stress during their first year of college, parents may choose to conceal information about their breast cancer diagnosis with their children. Privacy is defined as a feeling that one has the right to own private information, either personally or collectively (Morr Serewicz & Petronio, 2007).

Parents who are undergoing treatment for cancer may not wish to share the intimate details of their illness with their young adult children. Yet, young adult children may feel a sense of ownership over this information despite their geographical distance and separation from the situation. Also, boundaries are used to mark the ownership lines for each person as well as groups of people (Petronio & Durham, 2008). People manage multiple privacy boundaries surrounding not only personal information but also co-owned information with others.

These privacy boundary borders and the privacy rules used to regulate the information can be ambiguous or clear depending on the situation. Individuals may assume when they disclose private information to another that the content of the message is private, and clearly marked, and the privacy rules are obvious to the co-owners. However, the original owner may not have been clear about the privacy rules that the co-owners are expected to use. Unless the privacy rules regulating the boundary are clearly negotiated and understood by all who are privy to the information, the result may end in boundary turbulence (Petronio, 2002). Knowing the privacy rules parents expect children to use, particularly when navigating a parent's illness such as breast cancer that is complicated by distance and adjusting to a new living environment, is essential to helping the student cope with two very stressful situations (Arnett, 2000; Barnes et al., 2000; Erickson, 1964; Petronio & Ostrom-Blonigen, 2008).

Numerous privacy dilemmas likely arise in traversing the first year of college and the onset of breast cancer in the family, and the desire for privacy as well as disclosure between young adults and their families is a key element of this research study. Thus, CPM serves as an optimal lens for evaluating the privacy and disclosure of young adult students simultaneously addressing breast cancer and the first year of college (Petronio, 2002). This study proposes that the young adult's transition into college during the first year of college and the young adult's view of privacy and disclosure are significantly impacted when the family is faced with a life altering illness. Privacy and disclosure issues that arise for young adults and their families as they cope with breast cancer are multifaceted. There are many aspects that define the types of challenges young adults face in these circumstances. Each life transition, namely attending college for the first

time and encountering the difficulties of factoring in a parent with breast cancer, is complicated.

### Young Adult's College Transitions and Privacy Changes

In the case of a first-year college student exploring their own autonomy while dealing with their parent's medical crisis, this often results in a privacy dilemma for the child. The disclosure or concealment of private information within the family during the transition to college is just one of the numerous stressors that young adults can experience during their first year of college living away from home. Young adults often find this transition to be particularly stressful because in a short time the young adult must leave home, move into a new residence or dormitory without adult supervision, assume adult responsibilities, and learn to handle their own affairs (Bernier, Larose, & Whipple, 2005; Dyson & Renk, 2006; Kenny, 1987; Larose & Boivin, 1998). The transition to college is generally viewed as a positive step in life, but it has its challenges, especially for young adults who leave home in order to attend college (Dyson & Renk, 2006; Fisher & Hood, 1987; Struthers, Perry, & Menec, 2000). Transitioning to college requires adaptation to a new environment including social, academic, and residential challenges (Dyson & Renk, 2006; Fisher & Hood, 1987). During this time, new college students begin their transition from adolescence into adulthood (Dyson & Renk, 2006). As Arnett (2000) explains, "for most young people in industrialized countries, the years from the late teens through the twenties are years of profound change and importance" (p. 469).

One of the difficult facets of this family life cycle transition is that young adults work to establish autonomy while still maintaining a level of connectedness with their

families (Erikson, 1964). This period is marked by the adolescent's reduced involvement in family affairs as well as increased conflict in interpersonal relationships within the family (Callan & Noller, 1986; Erickson, 1964). During this time, the young adult must learn to traverse an unfamiliar university life, personal doubts about their abilities, and leaving home and separating from family (Dyson & Renk, 2006). Faced with various levels of stress and apprehension about leaving family, young adults also want a sense of autonomy. They wish to maintain ties with family while creating new privacy boundaries and rules (Dyson & Renk, 2006). This situation is significantly complicated by the diagnosis of breast cancer within the family. During a time when young adults are establishing their own autonomy, they must also navigate a life altering illness within the family which can have a substantial impact on their lives and hinder their adjustment process into college.

#### Impact of Breast Cancer and Changes in Family Privacy

This transition to college becomes considerably more complicated when the young adult's parent is diagnosed with breast cancer. The diagnosis of breast cancer generates momentous psychological and physical challenges for all family members, and this diagnosis adds a new variable to the young adult's already stressful first year of college (Edwards et al., 2008; Hilton & Koop, 1994). Breast cancer, in particular, has been widely associated with psychological and mental distress for the patient, and it invariably impacts the whole family (Hegel et al., 2006). Studies show that approximately one-third of breast cancer patients experience a considerable amount of distress as well as psychological impairment, and the disease impacts the whole family (Andrykowski et al., 2002; Badger, Segrin, Dorros, Meek, & Lopez, 2007; Coyne,

Palmer, Shapiro, Thompson, & DeMichele, 2004; Epping-Jordan et al., 1999; Hegel et al., 2006; Kornblith et al., 2003; Luecken & Compas, 2002). A breast cancer diagnosis has a propensity to permeate all aspects of life often causing significant psychological and emotional stress for many or all members of the family (Hegel et al., 2006; Badger, Segrin, Dorros, Meek, & Lopez, 2007). For instance, several research studies have found that the spouses and partners of cancer patients often experience higher levels of emotional distress including anxiety and depression than the patients themselves (Manne et al., 2003; Segrin et al., 2005; Segrin, Badger, Dorros, Meek, & Lopez, 2008; Segrin, Badger, Meek, & Bonham, 2006). This demonstrates the immense impact that a breast cancer diagnosis can have on members of the patient's family. The diagnosis and treatment of breast cancer inevitably affects other members of the patient's family, and it also affects the way family members address private issues during the life space of the illness.

#### *Turning to Family to Cope with Breast Cancer*

Breast cancer is one of the most frequently occurring cancers throughout the world and often has a psychological impact on women diagnosed with this disease (Karakoyun-Celik, Gorken, Sahin, Orcin, Alanyali, & Kinay, 2010). Women who undergo treatment for breast cancer often experience impaired body image, anxiety, and emotional distress which can lead to decreased quality of life and in some cases increased risk of mortality (Badger, Segrin, Dorros, Meek, & Lopez, 2007; Hsu, Wang, Chu, & Yen, 2010). The dependence on family members and friends and the family's ability to cope with the illness and its emotional and physical effects are critical factors in the patient's capacity to manage their illness (Karakoyun-Celik et al., 2010). In order to adapt

and cope with their breast cancer diagnosis and prognosis, patients most often turn to close family members and friends for support as opposed to formal healthcare professionals (Figueiredo, Fries, & Ingram, 2004; Pistrang & Barker, 1995). In this way, dealing with a devastating disease such as breast cancer has a significant impact on the family as well as the patient. During the course of this disease, it is often very difficult for family members to communicate and disclose information about breast cancer (Barnes et al., 2000). In some cases, patients desire to keep this information private while others disclose many details about the illness with their families (Barnes et al., 2000). Overall, patients are unsure of how or if to communicate with their family about their diagnosis. As a result of the complexity and impact of breast cancer on the family, each family member is affected by the disease in different ways.

#### *Managing New Privacy Rules and Boundaries In the Midst of Two Stressors*

For the young adult who is newly attending college away from home, the challenges are complicated by the fact that the child is plotting a route through this disease. The first year college student has added stressors above and beyond those found in the first year experience when faced with a parent with cancer. In addition, the fundamental changes that take place with a disease such as breast cancer may mean significant alterations of privacy rules both for the child and for the parents. Changing privacy rules and boundaries that might have either just been established by the young adult or changes that result in the young adult being privy to information heretofore considered confidential between the parents can be disruptive in new and different ways.

Privacy management shifts when a family member is diagnosed with cancer. For example, Petronio and Ostrom-Blonigen (2008) discuss how the family faces the

formidable challenge of focusing simultaneously on the present and the future. Along with deciding how to communicate about the disease, families must address the immediate practical and emotional tasks of the situation while establishing a course to navigate the complexities of their problem in the unknown future (Petronio & Ostrom-Blonigen, 2008). These patients are often significantly affected by the illness, and must rely on family members to make personal and private decisions on their behalf. In the midst of this challenge, patients tend to desire maintaining control over their private information and the course of treatment as a whole (Petronio & Ostrom-Blonigen, 2008). However, as the illness progresses, patients are often forced to share ownership of their information with their family members (Petronio & Ostrom-Blonigen, 2008). Thus, the illness has a significant impact on the entire family. Even though the young adults in this study are in the midst of a transition to more independence and autonomy, this study desires to examine if young adults must take a practical stance and assume more emotional responsibilities to help their parents during breast cancer treatment.

As the family learns to communicate differently in the midst of these stressors, family privacy rules and family roles often change to accommodate the onset of an illness (Petronio, Sargent, Andea, Reganis, & Cichocki, 2004). Out of necessity, the roles of family members are forced to change, including the role of the person who is ill (Cohen-Mansfield, Pappas-Gill, & Golander, 2006; Petronio, Sargent, Andea, Reganis, & Cichocki, 2004). During the time a patient is administered treatment, family members often must take on the responsibilities of managing the patient's healthcare (Piercy & Chapman, 2001). Thus, family members may find themselves in the role of informal healthcare advocates (Petronio, Sargent, Andea, Reganis, & Cichocki, 2004).



During the treatment process, the family member suffering from breast cancer must often give up control of numerous privacy boundaries while undergoing treatment for their illness (Petronio, 2002; Petronio & Ostrom-Blonigen, 2008). This can be a difficult process for both the family member who is ill and the rest of the family. As a result of these shared boundaries around the family member's medical information and care, people seek control and ownership of this content (Petronio, 2002). According to CPM, privacy is "the feeling that one has the right to own private information" (Petronio, 2002, p. 5). People feel a right to own certain information and controlling private information can be believed to protect them from vulnerability.

The young adult usually desires to establish different privacy boundaries from their family, but it is not apparent whether the young adult will still feel ownership over information regarding their parent's breast cancer. If different family members seek ownership over private information throughout the life space of the illness, this can cause conflicts within the family. Adversely, if the parents' desire is to shield their young adult child from the private details of the illness, this may also cause distress between members of the family. Consequently, these issues can lead to misunderstandings and confusion as the family seeks to establish new privacy boundaries while attempting to respect their family member's need for control and ownership over their private information. When coordination of privacy boundaries fails, boundary turbulence occurs.

According to Petronio (2002), boundary turbulence occurs "when people are unable to collectively develop, execute, or enact rules guiding permeability, ownership, and linkages" (p. 177). Learning to live with cancer may be difficult for the patient, but learning to cope with a loved one's diagnosis may be even more challenging as the

family plots a course through the control and ownership of privacy boundaries (Hilton, 1994; Petronio, 2002). Examining the communication process from the young adult's perspective with regard to how they received information from their parents about the illness provides unique input about how particular families may address private information while traversing maternal breast cancer. The college student living away from home may not be privy to many of the more intimate details of the treatment process, and the way they integrate into the life course of the illness may influence the way they disclose and communicate overall with their parents.

#### Parents' Communication with their College Students

As a whole, research demonstrates that family communication about the diagnosis and treatment process tends to become significantly more difficult in breast cancer situations (Jamison, Wellisch, & Pasnau, 1978; Northouse, 1988). The impact of cancer on children is lessened if there is communication with them to discuss all of the critical issues and to facilitate more effective psychological adjustment (Visser et al., 2004). However, when parents disclose their breast cancer diagnosis, this often creates unique privacy dilemmas for the young adult. CPM positions disclosure as revealing private information, in this case, about a disease that is viewed as extremely personal to the individual and the individual's family (Petronio, 1994). When an individual decides to include another in their privacy boundary, this requires boundary coordination. After a parent has been diagnosed with breast cancer, the individual must decide who, when, and how to share this information with family members and friends. If the parent is striving to establish new privacy boundaries with their first-year student, this highly stressful information may lead to intricate boundary coordination (Morr Serewicz & Petronio,

2007). The parent may choose to wait to disclose this information to their child until a more convenient time, or they may decide to share the information without regard to their young adult child's new life cycle change. CPM is established as a dialectical theory because people simultaneously feel forces pushing and pulling them to reveal or conceal information (Morr Serewicz & Petronio, 2007). This is certainly true for the parent as they work to balance their child's autonomy with the need for support through this difficult process. This is also true for the student who must navigate revealing and concealing this delicate information in their new environment.

#### Interface of Privacy Transitions in College and Parental Diagnosis of Breast Cancer

The transition during the first year of college can be particularly stressful for young adults, yet, this stress can be significantly exacerbated by a parent's diagnosis of breast cancer. This diagnosis can cause a significant psychological disturbance and stress for young adults attending college (Barnes et al., 2000; Edwards et al., 2008). Breast cancer is one specific area of oncology that has been studied extensively in relation to its impact on various members of the family (Blanchard, Albrecht, & Ruckdeschel, 1997; Edwards et al., 2008; Forrest, Plumb, Ziebland, & Stein, 2009; Lewis, 2004).

The complexity and stress of a breast cancer diagnosis is clearly evident and takes a toll on the family as a whole (Barnes et al., 2000). Complicating matters further, communication between parents and young adult children attending college for the first time can be strained as children work to establish independent privacy boundaries and autonomy (Petronio, 2002). Consequently, when a parent of a young adult child is diagnosed with breast cancer during their child's first year of college, the young adult is forced to navigate the already difficult process of communication with their parents while

they are away from home, the psychological and emotional stress generated from the diagnosis of a life altering illness, and the stresses of adapting to their first year of college life.

Research has focused on the young adult's transition to college and other literature has addressed the adolescent and young adult's experience with parental breast cancer, however, understanding how families adjust and cope when several stressors and life cycle transitions occur simultaneously has been left out of the equation. Yet, we know that significant research has established that the adaptation to college life is often difficult and stressful for young adults (Bernier, Larose, & Whipple, 2005; Fisher & Hood, 1987). Ample research also demonstrates the impact of parental breast cancer on children of all ages (Mosher & Danoff-Burg, 2005; Northouse & Peters-Golden, 1993). The dilemmas to reveal or conceal information are a key element present in both the research on the transition to college and on the impact of parental breast cancer on children. One of the ways to better understand this position of privacy for young adults facing the stresses of first year experiences in college and facing the added complication of a parent diagnosed with breast cancer is to use a theoretical lens. Communication privacy management (CPM) theory provides a ready framework from which to understand and analyze the way young adults regulate private information and accommodate the need for shifting privacy boundaries when they are faced with two stressful demands (Petronio, 2002; Petronio & Durham, 2008).

#### *Using the Theoretical Framework of CPM to Evaluate Two Simultaneous Stressors*

According to CPM, private information is placed at "the heart of disclosure" (Petronio, 2002, p. 258). In other words, all information that is disclosed is considered

private, and revealing or concealing is the method through which the individual manages this information. This is information that is considered inaccessible to others. As Petronio states, “to tell or not to tell is a condition that we frequently face, yet the question is complicated” (Petronio, 2002, p. 1). The breast cancer diagnosis comes at a time for the family when the student is supposed to be forming new and different privacy boundaries and may not be as actively involved in the intimate details of the family’s private information. Often parents work to find a new balance of privacy and disclosure with their child in order to be considerate of their student’s desire for autonomy and their child’s need for parental support during this difficult life cycle change (Callen & Noller, 1986). Looking at topic avoidance of adolescents and young adults in stepfamilies, Golish and Caughlin (2002) explain that the need to establish roles and boundaries may be especially pronounced for young adults and adolescents who are adjusting to new families while simultaneously seeking to establish their own separate identities. A first-year student is not necessarily dealing with adjusting to a new family, but he or she is faced with establishing new roles and boundaries in college while simultaneously working to maintain familial relationships.

The amount of information that is shared between various family members and the young adult is directly affected by this transition from high school to college (Petronio, 1994). Before entering college, young adults share much of their private information with family members, and the family as a whole has information that is jointly known and mutually cared for by all family members (Petronio, 2002). Petronio (2002) explains that “as children reach a point where they are considered independent, they form an individual set of criteria or rules for privacy regulation over information that

is considered personally private” (p. 165). As young adults create new social networks and explore their independence during the transition to college life, the boundaries around their private information expand to accommodate their increased privacy needs, and they form new but often different privacy rules along with the privacy rules they once had with their family members prior to leaving home (Petronio, 1994).

Thus, in addition to forming separate privacy boundaries from their families, they also establish their own set of privacy rules that regulate information they define as being separate from the kinds of issues they tell their parents (Youniss & Smollar, 1985). Consequently, privacy boundaries and the rules governing them that the young adult developed prior to enrollment in college are likely to shift considerably in some cases and very little in others. Nonetheless, there is shifting of privacy boundaries and information within the young adult’s domain (Petronio, 2002). As a result, the young adult may exercise more control over his or her private information which may reduce the depth and frequency of disclosures with family members (Martin & Anderson, 1995). Also, the amount of private information shared between the young adult and their family shifts in order to accommodate this transition from adolescence to young adulthood. This adjustment to college also adds another complex dimension to the already stressful diagnosis of parental breast cancer within the family.

The private and intimate nature of a breast cancer diagnosis may mean that parents are reluctant to fully include their first-year student in their privacy boundary. Even if the student is commuting to school and still lives with the family, the parents may question how much information to share with their child. If the child is living on a campus that is a considerable distance from the family, this can possibly add other

dimensions to the amount of private information freely shared between the student and their family.

### *The Three Boundary Coordination Operations of CPM*

There are three boundary coordination operations of CPM that factor into this discussion of disclosure between first-year students and their parents' fight with breast cancer. The first operation, linkage, involves the process of incorporating private boundaries into collective boundaries. The closeness or weakness of the relationship between the group members can influence the extent to which they are required to maintain the boundary rules held by the group (Petronio, 2006). This research explores how a child's new role as a college student may factor into the parent's decision to disclose the information to their child and how the student maintains or disregards the requirements of the privacy boundaries given their removed status within the family (Callan and Noller, 1986).

Boundary permeability serves as the second coordination operation and involves the difficulty or ease with which information moves through the established boundary (Morr Serewicz & Petronio, 2007). This can range from highly permeable to highly impermeable depending on how easily the information is shared with any confidant outside of the boundary. In this case, the disclosure of the breast cancer diagnosis may be shared easily within the family. However, it is possible that the student may be viewed as outside of the primary boundary due to geographical distance or distance created by the new life cycle stage. Also, the student may see the boundary as highly permeable or impermeable with their newly established social network which may lead to interesting implications.

The final coordination operation is boundary ownership which can belong to any individual who is part of the boundary. Yet, all members who share the information within the boundary share ownership (Morr Serewicz & Petronio, 2007). These co-owners are responsible for coordinating the management of their private information within the collective boundary (Petronio, 2002). For first-year students with a parent's diagnosis of breast cancer, coping with the illness is significantly complicated by distance and learning to grasp navigating a new life stage (Erikson, 1964).

#### *Boundary Turbulence: When Boundary Coordination Fails*

As demonstrated previously, communicative management of information that is private is an extremely difficult endeavor and sometimes this coordination fails (Petronio, 2002). When coordination fails, boundary turbulence occurs. In the case of a first-year student and his or her parents, there are many possible scenarios in which the student or parent could fail to properly traverse the rules established by the family and the evolving rules being established by the student. The student could fail to keep the privacy rules established by the family by sharing the information with other students who are outside the boundaries. The parents could also create boundary turbulence by transgressing their child's newly formed boundaries, by relying on their child too frequently, or by providing too much detail about the treatment process.

#### *The Goals of This Study*

With the guiding framework of CPM, this study explores the privacy dilemmas that arise for first-year students as they respond to their parents' disclosures of breast cancer and subsequent treatment while navigating their first year of college. Overall, based on the established research in the field on communication about breast cancer and



regarding the first-year college experience, the goal of this study is to discover whether or not the family establishes new privacy boundaries and rules around the breast cancer diagnosis and treatment, to examine whether the first-year student's experience in college is significantly complicated and altered by the news of a life threatening disease within the family, and to explore if the student's privacy rules and boundaries adjust to accommodate this new life cycle change and their parent's breast cancer diagnosis.

## METHOD

The objective of this study is to examine the way college students, in their first year at school, coped with learning that one of their parents was diagnosed with breast cancer. This research focuses on the first-year college student's perspective and seeks to analyze and evaluate the responses, feelings, and actions of young adult recipients to the disclosure of this intimate and private information during their first year of college. This study adds to the significant body of literature on the communication of breast cancer and the transition into university life by fusing these two significant stressors and evaluating them from the young adult's perspective. This study contributes to this body of research in a unique and valuable way. Thus, the following research question guides this study:

RQ: How do new college students cope with issues of privacy management when a parent has been diagnosed with breast cancer during their first year?

### Data Collection Methods and Respondents

This study uses a qualitative, case study approach to data collection. Identification of the cases that best represent the particular domain of this study calls for cases to reflect those where students in their first year college experienced a parent who was diagnosed with breast cancer. Cases included in this research targeted respondents who were from one to five years post-experience coping with a parent's diagnosis of breast cancer. Individual cases were excluded when they did not meet these criteria. This study, therefore, focuses on retrospective information of a perceptual nature to capture the students' perspectives of dealing with a parent's breast cancer while in their first year of undergraduate school. By using retrospective data, respondents will have had enough

time to gain perspective on their experiences during their first year of college, thus providing rich case descriptions.

### Procedure

Two cases with respondents living away from home during their first year of college were identified. These respondents were recruited through a snowball recruiting format. Local organizations and online breast cancer support groups were utilized to identify cases representative of the criteria in this study.

In addition to the online recruitment, respondents were also recruited directly on the campuses through seeking permission from faculty to ask students in classes their willingness to participate in this study. The campuses where recruitment took place represented large, urban institutions, large rural campuses, liberal arts colleges, and religiously affiliated universities. The online breast cancer support groups that were used to recruit included: Y-Me National Breast Cancer Organization, The Wellness Company, The Little Red Door Cancer Agency, Cancer Care, Inc., Revolution Health Group, National Breast Cancer, Cancer Compass, Susan G. Komen for the Cure, and Dana Faber Cancer Institute. Finally, respondents were recruited through a hospital's Embrace Program and the American Cancer Society. In these cases, after identifying the purpose of the study, the survivors were asked whether they had children who were in their first year of college when they were diagnosed with breast cancer. They were then asked if they were willing to provide contact information for their adult child or if they prefer to ask their adult children first whether they would be interested in participating in a study. Once a determination was made, the researcher contacted the adult child and ascertained

his or her willingness to participate in the study. A consistent contact script was utilized for recruiting in all of these situations (Appendix A-Contact Script).

### Interview Protocol

The interviewer explained and obtained informed consent from the respondents (Appendix B-IUPUI and Clarian Informed Consent Statement). A semi-structured interview protocol was administered to respondents by phone, on students' campuses in a private office, in the student's home, or on the campus where the investigators were employed. The respondent for Case Study 1 was interviewed by phone and the respondent for Case Study 2 was interviewed at her family's home located in a Midwest city. The respondents for these cases were interviewed. The interviews were audio recorded and transcribed. The consent form administered explained, in detail, the purpose of the study, their rights to terminate any time, and the voluntary nature of participation. Since the study is theoretically guided by the Communication Privacy Management theory, the questions were framed in terms of this theoretical structure and based on issues raised in previous research.

The structure of the protocol included first asking respondents general demographic questions (e.g. age and years completed in college), then the substantive questions addressed privacy management issues for the first-year students. The questions included such issues as, how they learned about their parents' breast cancer diagnosis, questions about the way they coped with their parent's illness during treatment, questions about how their parents wanted this information managed to those outside the family, questions about how their parents' illness impacted their ability to study and accomplish their academic goals, and how they handled the experience as they were becoming

familiar with college life (Appendix C-Interview Protocol). The transcribed interviews were analyzed using a qualitative approach of case study reporting and thematic analysis to determine the recurring themes representing the perceptions of the target respondents. The data were interpreted using the Communication Privacy Management Theory.

### Case Study Report

A case study reporting mode was used to represent the data in this study. Since the ultimate purpose of any report or research is to “improve the reader’s level of understanding of whatever the report deals with” (Lincoln & Guba, 1985, p. 358), case studies permit the reader to build on his or her own knowledge in ways that foster empathy and understanding of the subject. Also, case studies enable in-depth probing of an instance in question rather than merely providing a surface description of a multitude of cases.

Using a case study reporting method provides a “thick description” of how these respondents and their families managed privacy and disclosure in the midst of two significant stressors (p. 359). A case study approach clarifies the complexities of the two cases analyzed in this study and provides understanding of two different ways that young adult students might traverse the privacy and disclosure of their parent’s life threatening disease while attending college for the first time. These substantive case studies contain a description of the context in which the inquiry took place, a thorough description of the transactions during the interviews, and a discussion of the outcomes of the inquiry (Lincoln & Guba, 1985). Additionally, this study uses a thematic approach to evaluate these two cases.

### Thematic Analysis

A thematic analysis was used to understand the issues raised in these case studies and to identify patterns of experiences or behavior that emerged from these case studies (Aronson, 1994). A thematic analysis is useful in creating themes that “emerge from the informants’ stories” and are “pieced together to form a comprehensive picture of their collective experience” (p. 1). This research also utilized elements of Lindlof’s (1995) constant comparison thematic analysis process in which themes were developed based on underlying aspects of privacy management. The constant comparison method utilizes two steps, a first-order analysis and a second-order analysis, which are used to establish units, or critical incidents (1995). After the interviews were conducted, they were transcribed. The five suppositions of CPM were used as a lens for evaluating the transcribed content. Patterns that are consistent and divergent between the two cases began to emerge based on these suppositions.

### Interconnection of Case Study Methodology and Thematic Analysis

This study utilizes both a case study approach and a thematic analysis to identify the common and contradicting patterns that exist between the two cases studied. Reporting the data as individual case studies provides a rich description of each case. While developing these cases through the lens of CPM, themes naturally emerged that were congruent with the five suppositions.

## RESULTS

Overall, the findings of this research illustrate the different ways that students living out of the home coped with a mother who was diagnosed with breast cancer. The two cases were selected because they represent two drastically diverse experiences regarding a young adult's first year of college and their parents' breast cancer treatments. These cases may not represent what all families experience with regard to a young adult's first year of college and a parent's breast cancer diagnosis, but these cases do exemplify the ways in which families may navigate privacy and disclosure in the midst of these two concurrent stressors. Within and across these cases, a thematic analysis is conducted to identify recurring issues that identify both consistent and divergent issues these families and young adults face. The analysis identifies certain patterns that exist for families as they communicate about breast cancer and the young adult child's first year of college. Each case is discussed in detail and analyzed in reference to the five suppositions of CPM theory.

### Case Study 1

After attending community college for one semester in a Midwestern city where much of her family including her father, stepmother, and siblings lived, Ms. A, a Caucasian female, left her home and moved to a coastal state 2,000 miles away to live with her birth mother. While living with her birth mother, she attended a local community college. When asked if her family from home was okay with her move across country, she explained that they were supportive of her attending college but were concerned with the lifestyle she was leading when she lived with them in the Midwest. They feared that her "party" lifestyle would get worse once she moved away. Her family in the Midwest

was worried, but her birth mother was supportive of her move and of her attending college. Ms. A expressed that “it was challenging for me with moving from family to family and changing my home.” She explained that she had a close relationship with her family including her stepmother. She also explained that “trying to make new friends, trying to get used to school and get school going” was challenging. She admitted that during this time period she was “in with the wrong crowd” and involved in the “party seen.” In the midst of this, Ms. A said that there was “a lot of turmoil” and a “lack of communication” in her family over her decision to move across the country and over her increased partying.

#### *Disclosure of Breast Cancer*

During her second semester of freshmen year, her father called her and broke the news that Ms. A’s stepmother had been diagnosed with breast cancer. He said in a straightforward way that Ms. A’s stepmother had breast cancer, and he wanted her to come home to be with the family. Ms. A’s parents asked for her to return home due to her stepmother’s desire to take family pictures before her stepmother began to lose her hair from chemotherapy treatments. Ms. A’s response to this difficult news was a sense of disbelief. She said, “I’m pretty sure he just came out and said it.” Ms. A expressed that her father tried to make sure that she was okay and in a safe place when he broke the news of her stepmother’s illness. Later, Ms. A’s sister called and reiterated that “Mom’s got breast cancer.” In both conversations, Ms. A said that her father and sister told her “just the basics.” She said that it seemed her father did not know as much as her stepmother about the details of the illness or treatment. Unfortunately, Ms. A was in



school and did not feel she could leave immediately, so instead she agreed to return home two weeks later for her Spring Break.

When Ms. A and her older sister (at another out-of-state college) returned home for Spring Break, the first thing her stepmother did was disclose the details of her illness and treatment. She explained that she had inflammatory breast cancer which required a unique method of treatment. Ms. A commented that her stepmother “told her a lot in the beginning.” Ms. A stated that “we have a really close knit family,” “they all seem to come together really well in times of trouble.” Because of the closeness of her family, Ms. A admitted that the whole experience was “kind of traumatic” and was “like walking on eggshells” when she first went home to visit.

While she was away at school, Ms. A’s communication with her family increased while her stepmother was going through treatment. Ms. A noticed that the communication from her stepmother fluctuated. When her stepmother seemed to be doing well, Ms. A would talk to her family about once a week. However, when her stepmother was not doing as well, Ms. A would talk with her and other family members more frequently and for longer periods of time. If her stepmother was having a particularly difficult time due to treatments, Ms. A’s father frequently called to share the details of what was happening at home.

### *Coping with Two Stressors*

When Ms. A returned to college after visiting her family over Spring Break, she admitted that she “spiraled into kind of a depression” and “got into drugs and into drinking.” She said it was like she was “trying to run from it.” She liked the fact that her stepmother was very upfront with her about her treatment plan and what was really

happening with her, but, nevertheless, Ms. A said she was “overwhelmed with the details.” She began to feel that she did not really want to know more than she needed about what was going on at home. She found it difficult to handle her stepmother’s cancer, and, as a result, she could not bring herself to go home. Consequently, she delayed going home and was only there part of the summer.

As the stress mounted during her freshman year, Ms. A said she turned to alcohol and drugs to cope with the trauma of this experience. She found that she was unable to stop depending on alcohol and drugs even when she returned to help her stepmother during the chemotherapy and radiation appointments. She felt bad that she did this, particularly because Ms. A was also at home to help care for her little sister. She confessed that, “I was in an alcoholic induced state pretty much most of the time.” As seems inevitable, Ms. A’s grades began to drop during this traumatic time and there was a lot of conflict over Ms. A living so far away.

Ms. A felt badly because it was difficult for her to handle her stepmother’s illness and her family’s needs. She thought it best if she just disappeared. As a result, Ms. A stopped all communication with her family for approximately six months. The pressure Ms. A felt during this time precipitated her dropping out of school and turning to drinking and drug use. When Ms. A finally reunited with her family, the family had been hurt and confused about her choices. These family feelings kept a level of animosity and conflict alive because they could not understand her choice to disappear. The stress of life threatening cancer within the family, Ms. A’s addictions, and the tension within the family led Ms. A’s stepmother to encourage her entire family to enter into therapy. Ms. A strongly believed that therapy allowed their family to discuss what was really happening

within the family and helped each member cope with the illness and choices Ms. A made to handle the illness.

In the midst of her stepmother's cancer treatment, Ms. A's family made it clear that they wanted her to finish her education. So, Ms. A went back to school because she knew she needed to complete college. Even though she continued school, it was still difficult to overcome her feelings, and she admitted that she could have gotten better grades. Nevertheless, she focused on doing as well as she could to avoid academic probation. However, her stepmother's illness definitely affected her ability to concentrate. She said, "I was overwhelmed and consumed by the breast cancer thing." As a whole, Ms. A expressed that it was difficult to balance school and her stepmother's illness.

#### *Interface of Friends, Classmates, and Professors*

In her interview, Ms. A was asked about how she disclosed or protected the information about her stepmother and her substance abuse with her friends, classmates, and professors at school. Often she would "shut down" when anyone mentioned cancer, but she recalled times when she would disclose her stepmother's illness to friends in hopes that they would feel bad for her. With friends and classmates, she admitted that she would disclose her stepmother's breast cancer diagnosis for shock value. She also admitted that she used her stepmother's illness as an excuse in school as to why she had not completed projects on time. She would tell her professors that her stepmother experienced a "flare up" of the disease making it difficult for her to get her school work completed. Often she found the professors sympathetic, and they gave her extra time to

complete assignments. However, she admitted that at times she used it “like an excuse for everything.”

Despite using her stepmother’s illness as an excuse, she explained that she did have the opportunity to talk and cry about it with the few friends she had at the time. With her closest friend, she had the chance to discuss the unique type of cancer that her mother had. She mentioned that she felt as if she did a lot of informing people about her stepmother and about her specific kind of breast cancer. Her stepmother also took on the role of informer and “wanted to get the information out there because she did not want women to die from this.” It became important to Ms. A and her stepmother to advocate knowledge of breast cancer. Since then, Ms. A’s stepmother has turned this experience into a career and works for a breast cancer organization. Overall, Ms. A felt comfortable sharing with her closest friends the details about her stepmother’s treatment as well as information about “what was really going on” in her family.

#### *Family Handling Sensitive Information*

Ms. A was asked about how her family handled sensitive issues and information that may be considered private. She responded that her family was pretty open and forthcoming about sensitive issues and said, “we’ve always kind of been very open with what our family’s been going through.” However, when it came to discussing Ms. A’s drug and alcohol abuse, she said the family was “very hush hush” about discussing it with others because they were embarrassed that she was an addict. They did not address this with other people and within the family it was only discussed on a need-to-know basis as if there was always a “big pink elephant in the room.”

Ms. A explained that the breast cancer diagnosis encouraged her family to be more open and honest about what was really going on with regard to Ms. A's addiction. It caused her stepmother and father to reach out to other people outside the family to disclose this information. As a result, many of her family members pursued counseling. Even her older sister, who had been in denial about Ms. A's addiction, eventually began to open up. The breast cancer diagnosis also changed Ms. A's relationship with her parents. In light of these difficult circumstances, Ms. A and her family chose to discard their inside family drama from the past in an effort to build solidarity to support Ms. A's stepmother. The seriousness of her stepmother's breast cancer led Ms. A to communicate more openly with her family in order to rebuild her familial relationships.

As a whole, Ms. A said that the way her family relates to one another has changed since her stepmother's diagnosis. She said, "we were more open to talk about the horrible things in our lives" and more open with discussing the reality of what is happening in their family. This also extends to their ability to communicate sensitive information to people outside of the family. Overall, Ms. A said, the "one thing that really came up with the breast cancer was that you need to talk about it."

#### CPM Case 1 Analysis

CPM provides a conceptual framework for evaluating how people manage private information. In this case, CPM supplies a roadmap for illuminating the various ways that families might navigate privacy and disclosure of breast cancer with a young adult child while he or she is attending college for the first time. This analysis utilizes the five suppositions of CPM theory to evaluate how the families of Ms. A and Ms. B dealt with privacy and disclosure surrounding the diagnosis of breast cancer within the family.

### *Private Information*

The first supposition of CPM theory argues that “when we reveal, we disclose private information” (Petronio, 2002, p. 5). This information is content for which others are not privy. Thus, CPM places private information as the central element of disclosure (Morr Serewicz & Petronio, 2007). CPM defines private information as information that is inaccessible to others. Some literature suggests that self-disclosure of private information is equated with intimacy, however, CPM argues that intimacy is not an automatic result of self-disclosure (Parks, 1982; Petronio, 2002). Sharing private information might increase intimacy in some situations but may not result in closeness between the discloser and the confidant (Petronio, 2002; Petronio, Schiebel, & Snider, 1991; Morr Serewicz & Petronio, 2007).

In Case 1, Ms. A traveled home for Spring Break shortly after her stepmother’s diagnosis. Her stepmother had researched her type of breast cancer and openly shared with her family the details of what was going on with her treatment. At first, Ms. A recalls feeling “overwhelmed with the details.” She said she did not want to know more than she needed to know about her stepmother’s struggle with breast cancer because she was struggling to cope with this information. Individuals often find it difficult to process disclosed information when they are highly affected by the emotionality of the information (Pennebaker, 1995; Petronio, 2002). Petronio explains that patients as well as their families are likely to close down their privacy boundaries to the incoming information as a protective device (2002). This is indeed the struggle Ms. A faced after hearing the details of her stepmother’s diagnosis. As a result, Ms. A remembers turning

to alcohol and drugs to numb the pain of this experience and even recalls being in “an alcoholic induced state pretty most of the time” when she came home to visit her family.

Ms. A’s family remained very open and honest about her stepmother’s treatment process, but the gravity of the situation led to Ms. A separating herself from her family for several months. The pressure of school, her parent’s fight with breast cancer, and her burgeoning addiction to drugs and alcohol led Ms. A to “disappear” for a period of time. This case indicates that openness about private information can indeed lead to less intimacy in some situations (Parks, 1982; Petronio, 2002). Despite this turbulent time in Ms. A’s relationship with her family, she eventually reopened communication lines with her family and through therapy they were able to regain a closer relationship.

Despite Ms. A’s initial reaction to her family’s openness about her stepmother’s breast cancer diagnosis and treatment, Ms. A believes that this experience has changed how her family relates to one another. Her family has become much more open to talk about the “horrible things” going on in their lives. Overall, she believes this experience has brought her family closer, and she has learned that it is important to be open with one another about private information.

### *Privacy Boundaries*

The second supposition of CPM uses the metaphor of a boundary to demonstrate the borders that people place around information they own (Petronio, 1991, 2002). Just like the physical boundaries that people place around their possessions to indicate ownership, people also place boundaries around information they consider to be private and personally owned (Morr Serewicz & Petronio, 2007). Families will regulate both internal privacy boundaries which correspond to information shared within the family

and external privacy boundaries which govern the flow of communication to those outside the family (Petronio, 2002). When it came to information regarding the diagnosis and treatment of breast cancer in Ms. A's family, Ms. A recounted that during her first visit home on Spring Break it was as if they were "walking on egg shells." This was a new situation in their family, so they were unsure of the boundaries and rules that existed with regard to discussing this issue. They soon established highly permeable external and internal boundaries that allowed Ms. A's family to freely discuss this issue with one another and with those outside the family. Ms. A's stepmother decided to wear a scarf over her head once she lost her hair instead of wearing a wig that would better hide her illness. This demonstrated her willingness to reveal her illness to others. Also, she chose not to wear a prosthetic bra very often after undergoing her mastectomy. Even though Ms. A said her mother experienced depression during that time, they were very open about what was going on in their family. These two examples are indicative of the permeable boundaries that the family had regarding the disclosure of breast cancer.

Ms. A's family had very permeable boundaries regarding breast cancer, however, Ms. A recounted that her addictions to drugs and alcohol were clothed in highly impermeable boundaries. She said they "were very hush hush" about this issue and they often tried to cover up this private information so that those outside the family were unaware of the situation. Even within the family, Ms. A said her addiction was only disclosed on a "need-to-know" basis. When Ms. A disappeared from her family shortly after her stepmother's diagnosis, she created an impermeable boundary that prevented her family from knowing about her poor grades and increased drug and alcohol use. This created significant conflict within the family and caused them to worry. Petronio explains



that boundary turbulence can occur when people violate established levels of boundary permeability (2002). This relatively permeable boundary surrounding the family owned private information became an impermeable privacy boundary while Ms. A was away at school and her parents were dealing with this disease. Ms. A explained that there was “a lot of conflict around me disappearing.” Now that Ms. A has been sober for two years, her family’s privacy boundaries regarding her addiction have become significantly more permeable with both friends and family. Ms. A said that with friends and family, “they all know what is going on.”

### *Control and Ownership*

The third supposition of CPM explains that people feel ownership over their private information and seek to control the transmission of this information to others. People feel they have the right to control information because they believe they own this information. Also, people may choose to control this information to avoid vulnerability (Morr Serewicz & Petronio, 2007). Ms. A’s interview indicated that her stepmother believed the information about her breast cancer diagnosis and treatment to be jointly owned by her relatives even though this information was specifically related to her stepmother. Ms. A was given joint ownership of this information, but, at first, she chose to control this information by “shutting off” and trying to avoid hearing the details.

When Ms. A returned to school after visiting home over Spring Break, she struggled to remain focused on school. She admitted that she controlled this information while at school by using it as “shock value”, “an excuse”, and “an attention grabber” if she desired attention from others. At this time, her addictions became more severe and her grades began to drop. It is commonly reported that the psychosocial consequences of

substance abuse among adolescents include arguments with family and friends, financial difficulties, and problems at school (Coombes, Allen, Marsh, & Foxcroft, 2009).

Furthermore, Kandel et al. (1999) explain that substance misuse can result in antisocial behavior and is related to family problems and failure in school. Ms. A reported that conflicts arose with her family over her continued substance abuse, and she reported feeling overwhelmed with the details of her stepmother's illness. She decided to "disappear" rather than disgrace her family with the truth. During this time, she cut off all communication with her family in the Midwest and dropped out of school. In this way, Ms. A sought to control this information to avoid disclosing this to her family. Information that Ms. A's family was originally privy to was no longer available to them. This decision caused considerable boundary turbulence and led to significant worry and conflict within the family.

#### *Rule-Based Management System*

In order to control information that they consider to have ownership over, individuals will create rules around revealing or concealing their private information. Thus, CPM is a rule-based management system (Petronio, 2002). This system works for both individuals and for groups, but it is more difficult at the collective level due to the difficulty in coordinating rules for privacy management (Morr Serewicz & Petronio, 2007). In Ms. A's family, her stepmother quickly established rules that allowed the family to discuss the diagnosis with those outside the family. In fact, Ms. A's stepmother desired to share this information with others in the hope that it might raise awareness of her particular type of cancer. Ms. A said her stepmother "wanted to get information out there because she didn't want women to die from this." She also desired that the whole

family attend counseling and utilize resources for coping with breast cancer. This is congruent with research indicating that it is common for women to want to discuss with others their experiences with breast cancer (Janoff-Bullman, 1992; Mallinger, Griggs, & Shields, 2006; Rime et al., 1992; Rime, 1995).

Ms. A expressed that after she reconnected with her family after her disappearance she also took on the role of informer with her friends. She, too, desired to educate people about this particular type of cancer. Ms. A's stepmother had a rare type of breast cancer called inflammatory breast cancer (IBC). IBC is not well known by clinicians or by the general public because it does not present with the typical symptoms of breast cancer (Johnson et al., 2006). The necessity to educate others about IBC became an unspoken rule for Ms. A's stepmother as well as for others within the family because this disease is so rare and unknown. Also, within Ms. A's family, there were established yet unspoken rules about Ms. A's ongoing struggle with addiction. Ms. A said they did not talk about it unless it was absolutely necessary. Rather than revealing the real reason for Ms. A's absence from home, the family would often cover up her addiction by saying "she is at school."

As Ms. A's stepmother progressed through her treatment and after Ms. A was reunited with her family, these rules regarding Ms. A's addictions began to shift. Ms. A's stepmother encouraged the family to attend therapy sessions which allowed the family to discuss the "pink elephant" in the room. Since that time, Ms. A indicated that this rule has shifted drastically, and it appears that Ms. A's family now openly discloses this information to friends and family.

### *Privacy Management Dialectics*

The final supposition of CPM posits that people make decisions about how to handle private information based on “the simultaneous strength of their desires to disclose information and to protect their privacy” (Morr Serewicz & Petronio, 2007, p. 258). Thus, people feel forces concurrently pushing and pulling them to reveal private information as well as conceal information. Since, it is almost impossible to completely reveal or conceal information, people are left with the continuous decisions of whether to disclose private information or keep the information confidential.

When Ms. A traveled home for Spring Break shortly after her stepmother’s diagnosis, Ms. A recalled the feeling that everyone was “walking on eggshells.” They had not established privacy boundaries and rules that addressed how they should handle this new situation. Quickly they established new boundaries and rules for discussing the diagnosis in the family and with others.

### Case Study 2

Ms. B is an African American female who attended a university in the Midwest which was four hours away from her family’s home. While attending college, Ms. B ran track for her university. It was evident throughout the interview that Ms. B’s family greatly valued higher education. As a result, Ms. B’s family desired for her to focus on her education and on her sport without worrying about events occurring at home.

### *Disclosure of Breast Cancer*

During her summer break before heading off to college for the first time, Ms. B’s mother found a lump in her breast. Her mother informed the family that she was going to get a biopsy. It was not discussed much more after that until one night Ms. B’s mother

told Ms. B and her brother and sister that she had breast cancer. Ms. B said it was “really emotional” but her mother’s upbeat demeanor and positive attitude helped her deal with this information. Ms. B explained that her family is “not really a mushy family” and even her mom did not want them to cry or worry about her diagnosis. Also, Ms. B recalled that “everybody kind of catered” to Ms. B and made sure she was okay so that she would not be worried about going four hours away for college. Ms. B also believed that her mother told everyone in the family that she did not want this diagnosis to affect Ms. B’s first year at school. As a result, Ms. B was not given any extra responsibilities to help with her mother’s care. Ms. B also expressed that she felt no guilt over being away at college. Ms. B’s mother often made it clear that she was being well cared for by her sisters and other extended family in hopes that Ms. B would not be affected by her mother’s illness.

Ms. B recalled that “it didn’t hit me until she had surgery.” She said she as well as her siblings “didn’t understand the gravity of it” until her mother underwent surgery. Even after surgery, Ms. B said it was not much of a factor until her mother started chemotherapy and caught pneumonia. Ms. B’s mother spent several days in the hospital the week before Ms. B left for college due to her illness. With the support of her close aunts, Ms. B was able to get everything prepared for college. Even though her mother was in the hospital for an entire week, Ms. B said “surprisingly” this did not affect her college experience. Ms. B’s mother was still able to drive her four hours away to college the week after her stint in the hospital.

Ms. B’s mother’s illness did not affect her college experience because she was not there for the majority of her mother’s chemotherapy and radiation treatments. Also, Ms. B explained that the distance from home kept her from seeing her mother struggle

through the illness. The only time that her mother's illness affected her was when her mother and father came to visit her. Ms. B said her mother was "extremely tiny and bald" and this was "a little scary." She said she was not "expecting her to be so sick." Other than this experience, Ms. B reiterated that this did not affect her ability to remain focused at college.

#### *Communication with Family While Away*

Throughout her freshmen year, Ms. B communicated regularly with her family. Ms. B said she talked with her family about two times each week. Her father would fill her in on her mother's progress. For instance, he would share with Ms. B when her mother was forgetting things. Ms. B explained that her mother would get "chemo brain" and forget basic tasks like paying the water bill. In regard to her relationship with her mother, Ms. B said "we have a very close relationship but I don't talk to my mom every day." She explained that they would only talk on a "need to know basis" and her mother would only call if she really needed something. Overall, Ms. B's communication with her family was very purpose oriented and matter of fact.

#### *Interface of Friends, Classmates, and Professors*

Ms. B was also asked how she dealt with this information with friends and professors while she was away at school. She explained that she would "just tell them when it was appropriate." She also said "it was never really an issue I brought up very often." During her freshman year, she said she might have told her boyfriend, roommate, and possibly a few track teammates. She also expressed that she definitely did not tell any of her professors. She "did not want people to make a big deal about it" and she did not want people to feel sorry for her.

### *Methods of Disclosure within the Family*

Overall, Ms. B said her family has always been very candid with one another but often use humor to cope with sensitive information. She recalled that her sister and brother would call her mother “baldy” and they often “treated it like a joke.” Her family is willing to discuss sensitive information, but she also said that outside her extended family information such as her mother’s breast cancer was often kept private. She expressed that, “our family’s really close, so we don’t really find it necessary to tell a whole lot of people.” Even though Ms. B described her family as candid, she also said that they did not talk about her mother’s breast cancer treatment very much and if they “were not ignoring it” they “were more making a joke about it.” She also said that she did not know much about breast cancer, and she did not discover until years later that her mother had had the most aggressive form of breast cancer.

As a whole, Ms. B said that she believed her family was “a little bit more of an exception.” She explained that she did not believe they “took it as gravely as a lot of families.” She concluded that “it didn’t really impact me all that much in college” because of her mother’s positive perspective on her breast cancer diagnosis and treatment. She iterated that this experience helped put everything in perspective, but it did not change how her family communicated with one another.

### CPM Case 2 Analysis

#### *Private Information*

Several times throughout the interview Ms. B expressed that her family was close and willing to share private information within the boundary of the extended family unit. However, in the midst of this, it was also articulated that Ms. B’s family often focused on

communicating information that was most pertinent and often chose not to disclose many of the details of the private information. When asked how often Ms. B talked with her mother while at college, Ms. B said that while she and her mother have a very close relationship, they would communicate on a “need to know basis” and would only talk if there was something pertinent to discuss. After Ms. B’s parents disclosed the breast cancer diagnosis to the family, Ms. B said they “did not talk about it much.” If they were not ignoring the issue, they often made jokes about it. Ms. B explained that the sensitive information surrounding her mother’s breast cancer diagnosis and other private issues were often addressed with humor. For instance, after Ms. B’s mother lost her hair due to her cancer treatments, Ms. B’s sister and brother often affectionately called their mother “Baldy.” Overall, Ms. B explained that her family is very close and therefore willing to readily share basic private information. However, the intimate details of these sensitive issues were often ignored or treated with humor.

The disclosure within Ms. B’s family is reminiscent of a type of hit-and-run disclosure (Helft & Petronio, 2007). In their examination of the methods physicians use to disclose difficult diagnoses to patients, Helft and Petronio found that it is not uncommon for physicians to “dump” bad news or to be “insensitively blunt” when sharing difficult information (p. 808). Also, after sharing these grave truths, physicians may choose to retreat from the situation due to the emotional pressure, thus causing a hit-and-run disclosure. Along with physicians’ disclosure of bad news to patients, other research has demonstrated the angst people often feel when disclosing information that will potentially burden others (Petronio, Reeder, Hecht, & Mon’t Ros-Mendoza, 1996). People may opt for a hit-and-run delivery of bad news as a way to avoid additional



discussion or emotional distress (Helft & Petronio, 2007). Ms. B's parents did not literally disclose the information and then leave, but they stated the information and then established boundaries that encouraged Ms. B and her siblings to not inquire about the details of the illness and to avoid any emotional response.

In an article on how breast cancer is communicated and handled among African American women, Cohen found that out of the African American women interviewed, many did not believe talking about cancer was a "normal topic" within African American culture (Cohen, 2010). They expressed that breast cancer was not discussed often within their families out of fear of disrespecting an individual's privacy or a desire to prevent their families from worrying about the illness. These respondents explained that out of respect for their family member's privacy, they did not ask them about their cancer history or diagnosis. These respondents also avoided discussing breast cancer so as not to burden their family members or loved ones (Cohen, 2010). This was indeed true for Ms. B's family. The diagnosis was quickly disclosed to the family, but Ms. B expressed that few details were explained. Also, Ms. B's mother did not want to burden her daughter with information about her illness to insure that she was able to focus on her first year of college.

#### *Privacy Boundaries*

Several privacy boundaries became apparent as Ms. B discussed her family's communication about private information. First of all, Ms. B explained that sensitive information such as a breast cancer diagnosis and even financial issues were readily discussed within the family. This boundary encompassed all in the family including extended family. Ms. B explained that this boundary excludes those outside the family.

She said, “we don’t let a whole lot of people in” and “our family’s really close, so we don’t really find it necessary to tell a whole lot of people.”

Second, Ms. B explained that this boundary around private information only pertained to relevant information but not an in depth level of detail. Ms. B’s family was willing to share this information but did not dwell on it. As mentioned previously, basic private information was readily available to Ms. B’s family members, but more intimate details were rarely disclosed. For instance, Ms. B said that because they did not discuss her mother’s treatment very frequently, Ms. B was not aware until years later that her mother had had the most aggressive form of breast cancer. Also, she mentioned several times that she did not know many of the details of her mother’s breast cancer treatment while she was at home and away at school.

Finally, Ms. B explained that after her mother disclosed her diagnosis to her children. She desired that her other children not disclose any more details or information to Ms. B before she left for college in an effort to help Ms. B stay focused on attending college. Ms. B’s mother told everyone that she “didn’t want this to affect” her going away to school. As a result, Ms. B expressed that she did not feel remorse, worry, or guilt for not being home to help her mother, and she did not feel the desire to be involved in any other privacy boundaries regarding her mother’s treatment.

#### *Control and Ownership*

It was evident from the privacy boundaries established within her family, that Ms. B and her family felt a sense of ownership over this information. When asked about how she handled this private information with her friends and professors at school, Ms. B clearly had a strong sense of ownership over this information. Ms. B’s boundary around

her mother's breast cancer diagnosis led her to keep this information relatively private from those at school. She explained that she did not disclose this information to many people at college because she did not desire for friends to feel sorry for her. She said "it was never really an issue I brought up very often." As a result, Ms. B remembered that she might have shared this information with only her boyfriend, her roommate, and a couple track teammates. She told these few people because she thought they would want to know and would be offended if she had not disclosed this information to them. She thought that her friends would feel that they needed to help her or would be hurt because she did not tell them. This also indicates that as her close friends, she felt they had some ownership over this information as well. She was also adamant that she did not disclose this information to her professors or any other college staff. Ms. B and her family clearly felt ownership over this information and were careful to control who was privy to it.

#### *Rule-Based Management System*

In addition to controlling the transmission of this information that was owned by those within the family, Ms. B's family had an unspoken rule that governed the method by which the sensitive information was shared. They were willing to share private information with one another, but Ms. B's family often used specific methods by which to disclose and respond to private information. For instance, Ms. B explained that her family is "not really a mushy family" and when her mother told Ms. B and her siblings about her diagnosis, she did not want them "to cry or anything like that." Ms. B expressed that this first disclosure was difficult but the issue thereafter was often handled with humor or ignored completely. Families often develop privacy orientations that signify concretized rules (i.e. long standing rules agreed upon by all members within the

privacy boundary of how to navigate sensitive information) for which family members ascribe (Petronio, 2002). Based on these privacy orientations, the family unit also has expectations for how medical information concerning a family member “should” be disclosed (Petronio, 2002). Ms. B’s family had clearly established rules of how to navigate the disclosure of medical information within the family.

Along with a rule that governed how Ms. B’s family disclosed information, another rule that was evident related to the amount of information that was disclosed within Ms. B’s family. Ms. B’s comments indicated that her family often shared just the basics and did not feel the need to include many details when disclosing sensitive information. Ms. B was privy to the knowledge of her mother’s cancer diagnosis, but her mother desired for her to be outside the privacy boundaries that might have included additional details about her mother’s specific cancer and treatment path. She did not have control over all of the details of her mother’s treatment process partly because she was outside the privacy boundary while away at school. As a result, Ms. B said this experience did not have any great affect on her while attending college.

Another rule within Ms. B’s family related to who was privy to private information regarding Ms. B and her family members. Ms. B explained that because her family was so close, they did not feel the need to divulge private information to those outside their extended family. Ms. B specifically said that “outside of our extended family, we don’t let a whole lot of people in.” This demonstrates that Ms. B’s family often kept sensitive information within the boundary of the extended family.

### *Privacy Management Dialectics*

It was apparent that Ms. B may have deliberated over whom she should reveal the diagnosis to while at college because of their family rule that private information stays within the family. She did not wish her friends and teammates to “make a big deal about it”, but she also knew her close friends would be offended if this was never shared with them. This desire to simultaneously reveal and conceal information about her mother’s cancer diagnosis did not seem to greatly affect her at school because she did not feel a sense of ownership over the details of this diagnosis. As a result, she often expressed during the interview that she was able to focus on school and athletics rather than on revealing or concealing the information surrounding her mother’s breast cancer.

## DISCUSSION

Considerable research has shown that communicating about breast cancer can be difficult and significantly impacts people's abilities to emotionally and psychologically adapt to this life altering circumstance (Billhult & Segesten, 2003). Patients experience considerable distress over their breast cancer diagnosis and treatment, but their families also face a great deal of upheaval in their own lives (Billhult & Segesten, 2003; Kim & Given, 2008). These issues were clearly represented in these cases. However, the way that people handle this type of stress varies considerably as was found in the two very different approaches reflected in the cases. Ms. A, for example, experienced significant distress over her stepmother's diagnosis while she attended college. On the other hand, Ms. B expressed that her mother's diagnosis was difficult to cope with emotionally, but it did not interfere with her college success.

Each of these cases illustrates a different way in which a college student may deal with a mother's breast cancer diagnosis and provide unique insights into the reactions first-year college students might have to added stressors. Overall, a breast cancer diagnosis places considerable strain on family members particularly those who are responsible for care giving (Petronio & Lewis, 2010). These cases illustrate specific ways that particular college students managed privacy and meet the strain of living away from home during a time of stress in the family.

The cases in this study intentionally represent two cases with opposing ways that coping is accomplished. They illustrate two anchor points for levels of access and family privacy orientations. Ms. A's case is a stark comparison to case two in which Ms. B's family had a low permeability rule orientation and restricted disclosure internally and

externally. CPM theory uses the metaphor of a boundary to represent the lines distinguishing public and private information (Petronio, 2002). These boundaries “may be thick or thin, influencing the access to or protection of private information” (p. 99). CPM theory also explains that each family has privacy orientations that are used to regulate private information within and outside the family. Ms. B’s family had highly impermeable boundaries that limited outsiders’ access to any private information within the family. The interior boundaries within Ms. B’s family were also significantly less permeable than Ms. A’s family.

Each family owns and co-owns private information and each family has privacy rule orientations that govern who is privy to this information (Petronio, 2002). Based on CPM theory, there are exterior and interior boundaries within each family defining which family members are privy to different private information in the family. In case one Ms. A’s family had highly permeable interior and exterior boundaries regarding her stepmother’s breast cancer. All members of her family as well as those outside the family were allowed access to the details of her stepmother’s illness. In case two, Ms. B was only given moderate access to information about her mother’s illness because of her parents’ desire for Ms. B to focus on college. Ms. B’s family was willing to share pertinent information within the family, but the details of her mother’s illness were clothed in a highly impermeable boundary. This may be due to a desire to avoid discussing the illness so as not to disrespect their mother’s privacy or worry other family members (Cohen, 2010). The results of analyzing these cases adds support to Cohen’s (2010) findings on communication about breast cancer within African American female populations with regard to fear of worrying or burdening family members with this

information or desire to avoid this difficult topic so as not to disrespect a family member's privacy.

These two divergent cases provide anchors demonstrating different levels of access to private information within the family. These results indicate that other similar cases will fall between these two anchor points providing a guide for future research on this particular demographic. Using the five suppositions established by CPM theory, there are several key contrasts and similarities that exist between these two case studies.

#### *Differences Between Case Study 1 and Case Study 2*

There were multiple differences in the way in which Ms. A and Ms. B coped with private information about maternal breast cancer while transitioning to university life.

#### *Private Information*

Based on the interviews with Ms. A and Ms. B, their families managed private information in different ways. For instance, Ms. A expressed that her mother shared many of the details of her breast cancer with her family and those outside the family. As a result of these detailed disclosures, Ms. A recalled being “overwhelmed with the details” and this in turn had an adverse affect on Ms. A. This finding is consistent with existing research explaining that breast cancer patients often experience significant psychological distress and often turn to family members and friends to cope with their breast cancer diagnoses and treatment (Barnes et al., 2000; Epping-Jordan et al., 2008; Figueiredo, Fries, & Ingram, 2004; Karakoyun-Celik et al., 2010; Pistrang & Barker, 1995). In addition, friends and family members who are given co-ownership of this information also often experience adverse psychological affects (Billhult & Segesten, 2003). On the other hand, Ms. B explained that she did not know many of the details of her mother's



disease because her parents did not disclose this information to her and desired that she focus on school and not on this illness. Ms. B indicated that her family dealt with many private issues on a strictly “need to know” basis. This demonstrates Ms. A and Ms. B’s significantly diverse interior and exterior family privacy management orientations.

Along with a contrast between how these respondents communicated the details of their private information, Ms. A and Ms. B also coped with this information differently. The gravity of her stepmother’s breast cancer diagnosis greatly affected Ms. A and her family. The pressure of school and the seriousness of her stepmother’s illness eventually led her to drop out of school, break communication with her family, and give into her addictions. Fisher and Hood (1987) explain that the transition to university often causes academic and psychological stress. The stress of the transition to college combined with hearing the details of her stepmother’s illness proved to be too overwhelming for Ms. A.

Petronio (2002) explains that individuals may experience distress due to the burden of private information within the family. The confidant may feel they can exercise little control over the outcomes of the situation and over the discloser (2002). This distress over the burden of private information is true for Ms. A who felt a large burden regarding her stepmother’s diagnosis and treatment, yet she was powerless to control any of the outcomes of the situation. The privacy management style used in Ms. A’s family lead to her having a very open and accessible level of information about her mother’s illness. The result of this level of permeability meant that Ms. A had a greater sense of felt ownership and obligation to keep up on the information. She also felt a significant

sense of responsibility to her family, especially to her stepmother. As a consequence, however, Ms. A also felt an intense level of grief, pain, and worry.

Ms. A was greatly affected, but Ms. B recalled that it was difficult but did not have a significant impact on her first year of college. Ms. B's family had limited access to the information surrounding her mother's cancer, but Ms. B was not put in the position of taking any responsibility over the details of her mother's illness. As a result, Ms. B was able to remain focused on her studies while Ms. A was drastically affected by this burden. Ms. B's reaction is a unique finding in comparison to the research on the psychological effects of cancer on patients' family members (Billhult & Segesten, 2003; Karakoyun-Celik, et al., 2010; Segrin et al., 2005; Segrin, Badger, Dorros, Meek & Lopez, 2008; Segrin, Badger, Meek, & Bonham, 2006).

In addition, these two cases suggest that disclosure of the intimate details of a family member's illness can lead to increased ownership on the part of the young adult. In turn, the resultant level of this increased sense of responsibility and ownership may decrease the young adult's ability to simultaneously cope with the stress of attending college for the first time and supporting his or her family throughout cancer treatment.

Sharing private information within the family regarding their parent's illness also resulted in contrasting dynamic changes within the family. Ms. A argued that this experience brought their family closer together and caused more open privacy boundaries between the family members even though she struggled greatly through this time. Ms. B, on the other hand, argued that her family was already close and this experience did not change their family privacy orientations..

### *Privacy Boundaries*

Once Ms. A's stepmother shared her private information with the family and the privacy boundaries for this information were established, the family members were free to discuss this new information with the rest of the family and those outside the family. They often discussed the illness freely, but this highly permeable boundary did not extend to Ms. A's substance abuse. Ms. A's family created a highly impermeable boundary around her drug and alcohol abuse and this information was only discussed when necessary. Unlike Ms. A, Ms. B's family privacy boundary in reference to her mother's breast cancer related to only pertinent information and excluded those outside the family.

### *Control and Ownership*

Each respondent controlled her family's private information differently while attending college. Ms. A often used the private information concerning her stepmother's breast cancer as a way to gain sympathy from others, whereas, Ms. B specifically did not want others to feel sorry for her. Thus, she rarely shared this information in hopes of avoiding these sympathetic interactions.

### *Privacy Management Dialectics*

Both respondents sought to control how this sensitive information was shared with those at their colleges. This desire for control over this information led both respondents to feel the simultaneous desires to disclose the information and keep the information a secret. Ms. A desired to disclose her family struggles in order to gain sympathy. Yet, she also expressed that she often did not want to discuss the issues with others. Ms. B also felt the desire to remain private, but felt pressure to reveal this information with her close friends. Ms. B felt that because they were close friends, they

had some ownership over this information and had a right to know. However, she struggled to disclose the diagnosis with those at school because she did not wish for others' sympathy.

#### *Similarities Between Case Study 1 and Case Study 2*

These cases provide anchors for looking at the two extremes of the privacy orientations of families who cope with a mother's breast cancer diagnosis while their young adult attends college for the first time. There are also some unique similarities that exist between these cases. First of all, though both respondents had different ways of handling private information and privacy boundaries, neither Ms. A or Ms. B desired to hear many of the details of the diagnosis or treatment process. Both felt a sense of ownership over the general information and consequently, both sought to control how this sensitive information was shared while at university. Finally, while at school, both felt simultaneous pulls to reveal and conceal private information about the illness. As a whole, this study provides unique insights into two cases of the opposite reactions that a college student might have when dealing with the stress of the first year of college and a mother's breast cancer diagnosis. Case one offers an in depth example that contributes to existing literature on the impact of maternal breast cancer on family members (Billhult & Segesten, 2003; Kim & Given, 2008; Segrin et al., 2005; Segrin, Badger, Dorros, Meek, & Lopez, 2008; Segrin, Badger, Meek, & Bonham, 2006) and the stress of the transition to the first year of college (Dyson & Renk, 2006; Fisher & Hood, 1987). These cases also contribute insight into a demographic that has not been researched extensively in reference to maternal breast cancer within the family. These findings with regard to the difference in response for these two women may have been influenced by the families'

privacy boundaries – either open and permeable or closed and impermeable. Ms. A's family disclosed to her many of the details of the illness. Whereas, Ms. B's family tended to close the privacy boundary surrounding the details of her mother's cancer diagnosis and deliberately kept the details from her so that she was more able to focus on school.

These respondents may have reacted differently to major stressors in their lives, at least in part, because the expectation and actual sense of ownership and control over this information was differentially regulated by their parents. Ms. A and her family worked to maintain familial privacy boundaries; Ms. B had the opportunity to create privacy boundaries of her own while away at school. Unfortunately, Ms. A tried to gain personal control over her life through drugs and alcohol, further complicating her situation. This study adds credence to the fact that family members along with the patient regulate the flow of information, make decisions about who is privy to the information, how they are told, and the amount of information shared (Petronio & Lewis, 2010). Even while attending college away from home, both respondents contributed to the flow of information within their families. This study provides insight into two contrasting examples of how first year college students may balance multiple role demands in the midst of a parental breast cancer diagnosis. This evaluation provides a basis for further research on how families with college students traverse communication about cancer within the family. These results can also be used as a starting point for evaluating more broad populations such as the coping skills of all college students to maternal breast cancer or communication with young adults about multiple forms of cancer.

## APPENDIX A

### **Contact Script for Respondent Recruiting**

Good morning/afternoon \_\_\_\_\_, my name is Shannon Lewis. I am a graduate student at IUPUI (Indiana University Purdue University of Indianapolis) and I am currently working toward my Master of Arts degree and conducting research for my graduate thesis. My advisor, Dr. Sandra Petronio, and I are recruiting participants for a research study on families with a parent who was diagnosed with breast cancer. We are interested in interviewing adults whose parents were diagnosed with breast cancer during their first year of college. We are interested in understanding how they learn about the breast cancer diagnosis and the way the family conveyed information about the prognosis and treatment of the illness to the young adult during their first year of college. We would also like to know how they might have responded to their family members and friends about this information. Finally, we are interested in how the experience of a parent being diagnosed with breast cancer impacted the first year experience under these circumstances. This study has been approved by the Institutional Review Board at IUPUI to conduct this research and to interview young adults to gather data. I am wondering if I might be able to contact individuals through your organization to find possible participants. I would be willing to send you more information on my study as well as the documents indicating the Institutional Review Board's approval of this study.

## APPENDIX B

### **IUPUI and CLARIAN INFORMED CONSENT STATEMENT FOR**

#### **An exploration of privacy management issues that arise for first-year college students dealing with their parents' breast cancer diagnosis and treatment.**

You are invited to participate in an exploration of how family members talk about breast cancer to other family members and to their friends. This consent form explains the nature of this research, your rights, and how we are asking for your participation. Please ask any questions you might have before agreeing to answer our questions.

The study is being conducted by Shannon Lewis who is currently an Applied Communication Master's student at Indiana University-Purdue University of Indianapolis in the Department of Communication Studies. This research will be conducted in partial fulfillment of Shannon Lewis' Master's thesis under the direction of Dr. Sandra Petronio, her advisor.

#### **STUDY PURPOSE**

The purpose of this study is to understand how students, in their first year of college, viewed information that was communicated within the family when a parent was diagnosed with cancer. We would like to understand your experiences and find out how your family handled communicating about the illness when the student was away from home. By talking with you, we hope to develop a deeper understanding of your family experiences and gain insights into the way you handled learning about and tracking events of your parents' breast cancer diagnosis, prognosis, and illness overall. With the information we gather, we will be able to illuminate the issues faced by first-year college students when their parents becomes ill.

#### **NUMBER OF PEOPLE TAKING PART IN THE STUDY**

If you agree to participate, you will be one of 15 adults who will be participating in this research.

#### **PROCEDURES FOR THE STUDY**

If you agree to be in the study, we request you follow the procedure outlined below:

Participate in a brief interview session conducted by the co-investigator of this research study. We will be asking you questions about your family and about the time period when your family was dealing with breast cancer. Some questions you might be asked include: 'How did you find out about your parent's breast cancer diagnosis?' and 'What frustrations did you experience during your first year of college as a result of learning the diagnosis?' These interviews will be documented by using audio recording devices. The interview is expected to take approximately 1 hour.

Following the initial interview, you may be asked to participate in a subsequent interview for the purpose of clarifying and developing points brought up in the first interview. These interviews will be documented using written notes and will be recorded.

## **RISKS OF TAKING PART IN THE STUDY**

While you have the opportunity to terminate the interview at any time, we understand that the experience we are interested in was stressful. We will be asking in some depth about the feelings you had about the flow of communication to and from your family regarding your parent's illness. We will also ask how coping with your parent's disease impacted your college experience. Obviously, these questions will ask you to think about your encounters concerning this illness. However, please know that you do not have to answer questions that make you feel uncomfortable. Should you decide that certain questions or the whole study makes you feel uncomfortable and you decide that you do not wish to participate, you may request to move on to the next question or stop the interview at any time. You should also know that the interviews will be audio-recorded but only for strictly research purposes. You may feel uncomfortable with the interview being taped. If you do not desire to be audio-recorded, the interviewer can stop the recording at any time. If there is an occasion where suspected abuse or illegal activities appear to have occurred, the researchers may be forced to disclose the subject's information if required by law.

## **BENEFITS OF TAKING PART IN THE STUDY**

The benefits of participating that are reasonable to expect include the ability to tell your experiences more clearly and the opportunity to consider the meaning of the experiences you had with this period of your life. Research shows that when individuals have emotional challenges, such as facing a parent's illness, talking about it and examining it help to clarify feelings and objectively see the larger picture. Participation may be of benefit to you in this way. In addition, your insights are likely to help others better understand family who are experiencing an illness such as breast cancer, and specifically identify how young adults in their first year of college cope with both the stresses of entering a new and unexplored environment and also meet the challenges of dealing with the emotional impact of a parent diagnosed with cancer. You may even gain a deeper understanding of your family and a greater appreciation of you and your family's strengths.

## **ALTERNATIVES TO TAKING PART IN THIS STUDY**

If you do not wish to participate in this study, we will not interview you. There is NO penalty for declining participation in this study.

## **CONFIDENTIALITY**

Efforts will be made to keep your personal information confidential. We cannot guarantee absolute confidentiality, because there is always the slim possibility, for instance, that an audio recording could be lost. Your personal information may be disclosed if required by law. For instance, if, during the course of the interview, we hear about child or elder abuse, that would have to be reported. Your identity will NOT be disclosed in reports in which the study may be published.

At the end of the interview, all original information, including notes and recordings, will be de-identified and kept in a secure desk in the office of Dr. Sandra Petronio. As well, any computer containing files relating to this study will be password protected. Notes will be de-identified and



saved in order to have the possibility of writing up anonymous descriptions for publication. All files, notes, and recordings will be destroyed at the completion of the study.

Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the study investigator and his/her research associates, the IUPUI/Clarian Institutional Review Board or its designees, study sponsor, and (as allowed by law) state or federal agencies (specifically the Office for Human Research Protections (OHRP) and the Food and Drug Administration (FDA).

## **COSTS**

There are no costs for your participation in this study.

## **PAYMENT**

You will not receive payment for taking part in this study.

## **COMPENSATION FOR INJURY**

As this is a non-medical research study, there will likely be no injuries due to the research. However, as human subjects protections demand the notification of such items, in the event of physical injury resulting from your participation in this research, necessary medical treatment will be provided to you and billed as part of your medical expenses. Costs not covered by your health care insurer will be your responsibility. Also, it is your responsibility to determine the extent of your health care coverage. There is no program in place for other monetary compensation for such injuries. However, you are not giving up any legal rights or benefits to which you are otherwise entitled.

## **CONTACTS FOR QUESTIONS OR PROBLEMS**

For questions about the study or a research-related injury, you may contact Dr. Sandra Petronio at 317-274-8655.

If you feel the need to speak to someone about the information discussed during the interview, please contact Linda Bell, LMFT, ABPP, Ph.D. at 317-274-0299.

For questions about your rights as a research participant or to discuss problems, complaints or concerns about a research study, or to obtain information, or offer input, contact the IUPUI/Clarian Research Compliance Administration office at 317-278-3458 or 800-696-2949.

## **VOLUNTARY NATURE OF STUDY**

Taking part in this study is completely voluntary. You may choose not to take part or may leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled. Your decision whether or not to participate in this study will not affect your current or future relations with Indiana University, the investigator, or the co-investigator.

## **INFORMED CONSENT**

In consideration of all of the above, I give my consent to participate in this research study. I will be given a copy of this informed consent statement to keep for my records.

SUBJECT'S SIGNATURE: \_\_\_\_\_ Date: \_\_\_\_\_

## APPENDIX C

### Interview Protocol

**Title of Research Project for Thesis:** Between two worlds: An exploration of privacy management issues that arise for first-year college students dealing with their parents' breast cancer diagnosis and treatment.

**Principle Investigator:** Sandra Petronio, PhD

**Co-Investigator:** Shannon Sweeney Lewis

#### Introduction

To facilitate note-taking, we would like to audio-record our conversations today. For your knowledge, all information linking your name to the responses you give in this interview will be de-identified. We will use identification numbers on your responses and only researchers on the project will have access to your names. The tapes will be transcribed, however, the transcriber will not have access to your name. We will use the identification number for each interview that will not be associated with any names of participants. Once the information is assessed, the recordings will be destroyed. In order to participate in this interview, I need you to sign a consent form devised to meet our human subject requirements at IUPUI. Thank you for agreeing to participate. (Before the consent form is signed, all its elements will be explained in detail.)

This interview will last approximately one hour. During this time, you will be asked several open-ended questions about your experiences. I have several questions that I would like to cover.

We are interested in learning about your experiences during your first year of college while your parent was diagnosed with breast cancer. We are interested in learning about how you dealt with your parent's breast cancer diagnosis and treatment while attending college for the first time. We desire to learn more about the elements and characteristics of your family.

#### Background Information

Before we begin the questions about your first year of college and your parent's breast cancer diagnosis, I would like to ask you some background information. Please fill out this form.

Please read the following questions and answer accordingly.

1. How old are you?

18-20              21-23              24-34              35-45              46+

2. What is your ethnicity?

African American  
Asian  
Caucasian  
Hispanic  
Native American  
Other

3. Do you have any siblings?              Yes              No

If so, how many siblings do you have?

1              2              3              4              5              6+

4. How many years of school have you completed?

Less than 1 yr.    1 yr.    2 yrs.    3 yrs.    4 yrs.    5+yrs.

5. Who in your family has attended college? Please circle any that apply.

mother	father	maternal grandmother	maternal
grandfather			
sibling(s)	cousin(s)	paternal grandmother	paternal
grandfather			
aunt(s)	uncle(s)		
Other:_____			

6. How many in your family have completed a degree in higher education?

mother	father	maternal grandmother	maternal
grandfather			
sibling(s)	cousin(s)	paternal grandmother	paternal
grandfather			
aunt(s)	uncle(s)		
Other:_____			

Now, we would like to talk to you about your communication within your family regarding your parent's breast cancer diagnosis. We are interested in understanding how you learned about the breast cancer diagnosis and the way your family talked to you about the diagnosis and treatment of the illness during your first year of college. We would also like to know how you responded to your family members and friends about this information. Finally, we are interested in how the experience of your parent being diagnosed with breast cancer affected your first year of college.

1. To start, please tell me about your first year experience in college.

Probe: How did your family deal with you being at college?

2. Please describe when (month, time of day, etc.) during your freshman year and how you were told about your parent's breast cancer.

Probe: Who told you about it?

Probe: How did they tell you?

Probe: Were they very specific and detailed or more vague?

Probe: Why do you think they chose that specific time to tell you about the breast cancer?

Probe: When were you told about your parent's diagnosis? In other words, were you one of the first to be told, one of the last to be told, or somewhere in the middle?

Probe: Do you know why they told you in that order in comparison to others?

3. What was that like for you during the following weeks/months after you were told about your parent's diagnosis?

Probe: How did this experience in your family affect your college experience?

Probe: Did the information affect your ability to focus, interact, concentrate in school?

Probe: How often did you talk to your family after they broke the news to you?

Probe: Were you given any responsibilities (tasks, jobs) in light of the diagnosis or did you assume any extra responsibilities in order to help your parents/family?

Probe: What was is like balancing (juggling, dealing) both school and issues at home?

Probe: How did you address your parent's breast cancer diagnosis with your friends, acquaintances, etc. at school?

Probe: Were you open with people about the diagnosis and prognosis or did you keep the information to yourself or your close friends?

Probe: Did you tell any of your professors about it?

4. Tell me about how your family handled private issues (sensitive information, embarrassing issues, things that are generally very personal and private) before the cancer diagnosis.

Probe: Did this change at all during the time you were dealing with treating the cancer?

Probe: Did this information about your parent's diagnosis change your relationship with your parents or change how you talk to each other?

Probe: Do you think dealing with cancer changed how you talked to each other within the family? If so, how?

Probe: Did any conflicts or arguments arise about these personal issues (sensitive information) while your parent was being treated for cancer?

Probe: Did any of the conflicts have to do with you being away at school?

Probe: What were the disagreements about?

Probe: What were the surprises that they didn't tell you about until after?

5. How has your parent's breast cancer changed how you and your family relate to one another (talk to each other, value each other, interact with each other)?

Probe: How do you handle private information, personal information like breast cancer now that you've been through this experience?

Probe: Do you find that you are more willing to talk about private intimate information or do you think this experience has made it more difficult to talk about private issues?

## APPENDIX D

### INTERDEPARTMENTAL COMMUNICATION Research Compliance Administration (RCA) Indiana University - Purdue University Indianapolis

DATE: April 13, 2010

TO:

FROM: Pete King  
Research Compliance Administration

SUBJECT: Final Approval

Study Number: 0911-56B

Study Title: Between Two Worlds: An Exploration of Privacy Management Issues That Arise for First-Year College Students Dealing With Their Parents' Breast Cancer Diagnosis and Their Parents' Breast Cancer Diagnosis and Treatment - Sponsor: N/A

The study listed above has received final approval from the Institutional Review Board (IRB-01). Please note that subjects must be provided with and sign a current informed consent document containing the IRB approval stamp.

**Special requirements for the inclusion of prisoners:** Please note that unless your study has received approval for the inclusion of prisoners, you may not enroll and/or otherwise involve a prisoner in your study. Special requirements apply if an individual enrolled on the study either is a prisoner or has become a prisoner during the course of his/her study participation (and the study has not been previously granted approval for the enrollment of prisoners as a subject population). If the investigator becomes aware that a subject is a prisoner, all research interactions and interventions with the prisoner-participant must cease. If the investigator wishes to have the prisoner-participant continue to participate in the research, Research Compliance Administration (RCA) must be notified immediately (317-274-8289). In most cases, the IRB will be required to re-review the protocol at a convened meeting before any further research interaction or intervention may continue with the prisoner-participant. Refer to the IUPUI/Clarian Standard Operating Procedure (SOP) on *Vulnerable Populations* for further information. The SOP is available at [http://researchadmin.iu.edu/Forms/human\\_subjects/hs\\_iupui/Standard\\_Operating\\_Procedures%20\\_03%2008.pdf](http://researchadmin.iu.edu/Forms/human_subjects/hs_iupui/Standard_Operating_Procedures%20_03%2008.pdf).

As the principal investigator of this study, you assume the responsibilities as outlined in the SOP on *Responsibilities of Principal Investigators*, some of which include (but are not limited to):

1. **CONTINUING REVIEW** - A status report must be filed with the IRB at least annually. The RCA staff will generate these reports for your completion. This study is approved from April 12, 2010 to April 12, 2011. If your study is not re-approved by this date, the study will automatically expire, which means that all research activities, including enrollment of new subjects, interaction and intervention with current participants, and analysis of identified data, must cease.
2. **STUDY AMENDMENTS** - You are required to receive prospective approval from the IRB for ANY changes to the research study, including changes to protocol design, dosages, timing or type of test performed, population of the study, and informed consent statement, prior to implementation. This request is made via an amendment form, which can be obtained at: [http://researchadmin.iu.edu/HumanSubjects/IUPUI/hs\\_forms.html](http://researchadmin.iu.edu/HumanSubjects/IUPUI/hs_forms.html).
3. **UNANTICIPATED PROBLEMS INVOLVING RISKS TO SUBJECTS OR OTHERS AND NONCOMPLIANCE** - You must promptly report to the IRB any event that appears on the *List of Events that Require Prompt Reporting to the IRB*. Refer to the SOP on *Unanticipated Problems Involving Risks to Subjects or Others and Noncompliance* for more information and other reporting requirements. The SOP can be found at: [http://researchadmin.iu.edu/Forms/human\\_subjects/hs\\_iupui/Standard\\_Operating\\_Procedures%20\\_03%2008.pdf](http://researchadmin.iu.edu/Forms/human_subjects/hs_iupui/Standard_Operating_Procedures%20_03%2008.pdf). NOTE: If the study involves gene therapy and an event occurs which requires prompt reporting to the IRB, it must also be reported to the Institutional Biosafety Committee (IBC).
4. **UPDATED INVESTIGATIONAL BROCHURES, PROGRESS REPORTS and FINAL REPORTS** - If this is an investigational drug or device study, updated clinical investigational brochures must be submitted as they occur. These are submitted with an amendment form. Progress or final reports must be provided to the IRB with your written assessment of the report, briefly summarizing any changes and their significance to the study.
5. **ADVERTISEMENTS** - You can only use IRB-approved advertisements to recruit participants for your study. If you will be advertising to recruit study participants and the advertisement was not submitted to the IRB at the time your study was reviewed and approved, a copy of the information contained in the advertisement and the mode of its communication must be submitted to the IRB as an amendment to the study. These advertisements must be reviewed and approved by the IRB PRIOR to their use.
6. **STUDY COMPLETION** - You are responsible for promptly notifying the IRB when the study has been completed (i.e. there is no further subject enrollment, not further interaction or intervention with current participants, including follow-up, and no further analysis of identified data). To notify the IRB of study completion, please obtain a Continuing Review - Closeout Report form at [http://researchadmin.iu.edu/HumanSubjects/IUPUI/hs\\_forms.html](http://researchadmin.iu.edu/HumanSubjects/IUPUI/hs_forms.html) and submit it to the RCA office.
7. **LEAVING THE INSTITUTION** - If the principal investigator leaves the Institution, the IRB must be notified as to the disposition of EACH study.

PLEASE REFER TO THE ASSIGNED STUDY NUMBER AND THE EXACT TITLE IN ANY FUTURE CORRESPONDENCE WITH OUR OFFICE. In addition, SOPs exist which cover a variety of topics that may be relevant to the conduct of your research. Please visit [http://researchadmin.iu.edu/Forms/human\\_subjects/hs\\_iupui/Standard\\_Operating\\_Procedures%20\\_03%2008.pdf](http://researchadmin.iu.edu/Forms/human_subjects/hs_iupui/Standard_Operating_Procedures%20_03%2008.pdf) for a current copy of the IUPUI SOPs for Research Involving Human Subjects. All documentation related to this study must be neatly typed and must also be maintained in your files for audit purposes for at least three years after closure of the research; however, please note that research studies subject to HIPAA may have different requirements regarding file storage after closure. If you have any questions, please call Research Compliance Administration at 317/274-8289.

Please see the IRB approval email attached to this document, as well as the Documentation of Review and Approval, for a list of all documents approved with this submission.

IUPUI/CLARIAN INSTITUTIONAL REVIEW BOARD (IRB) REVIEW

STUDY AMENDMENT

Reviewing IRB (please choose one):

IRB STUDY NUMBER: 0911-56B

☒ IRB-01 ☐ IRB-02 ☐ IRB-03 (Methodist) ☐ IRB-04 ☐ IRB-05

AMENDMENT NUMBER: 1

DOCUMENT DATE: March 30, 2010

Please type only in the gray boxes. To mark a box as checked, double-click the box, select "checked", and click "OK".

SECTION I: INVESTIGATOR INFORMATION

Principal Investigator: \_\_\_\_\_ Department: Communication Studies  
(Last, First, Middle Initial)

Building/Room No.: \_\_\_\_\_ Phone: \_\_\_\_\_ E-Mail: \_\_\_\_\_

Contact Information:

Name: \_\_\_\_\_ Address: \_\_\_\_\_ Phone: \_\_\_\_\_  
Fax: \_\_\_\_\_ E-Mail: \_\_\_\_\_

Project Title: **Between Two Worlds: An exploration of privacy management issues that arise for first-year college students dealing with parents' breast cancer diagnosis and treatment**

Sponsor/Funding Agency: \_\_\_\_\_ Sponsor Amendment No. \_\_\_\_\_

SECTION II: STUDY INFORMATION

This study is:

- ☒ Open to enrollment  
☐ Closed to enrollment

Number of active subjects: 3

SECTION III: AMENDMENT DESCRIPTION

1. Provide a complete description of the proposed change(s) included in this amendment:

In the approved IRB proposal we indicated within the INCLUSION/EXCLUSION section that we excluded individuals with parents diagnosed with breast cancer in their first year of college who are five or more years from the experience. We wish to amend that to include those individuals who are one to five years or more post graduation from the experience and their undergraduate programs.

2. State the justification/rationale for this amendment:

We believe that the events are sufficiently memorable to incorporate a larger potential pool of people.

3. Is the study sponsored?

- ☒ No.  
☐ Yes. Check the appropriate line below and provide with this amendment, as applicable:  
☐ a copy of the sponsor's amendment, if the amendment came from the sponsor.  
☐ a copy of your notice to the sponsor of this change, if you initiated the amendment.  
☐ a copy of the approved amendment will be sent to the sponsor.

4. Do the proposed change(s) described in this amendment alter the risk to benefit assessment?

- ☒ No.  
☐ Yes. Please describe how the assessment is altered:

5. Do the proposed change(s) described in this amendment affect any of the following documents?

- ☒ Summary Safeguard Statement ☐ Authorization

v05/01/09



- ☐ Advertisement
 ☐ Protocol  
☐ Clinical Investigator's Brochure (CIB)
 ☐ Other, Please describe:

NOTE: Any document selected above must be included with the submission of the amendment.

6. Do the proposed change(s) described in this amendment require changes to the informed consent and/or assent document(s) or process?
- ☐ No. Informed consent, written documentation of informed consent, and/or assent has been waived for this study.  
☒ No. Skip to item 7 below.  
☐ Yes. Answer items A. and B. below.
- A. Check the appropriate line below.
- ☐ The new informed consent and/or assent document(s) are in addition to the current one(s).  
☐ The new informed consent and/or assent document(s) replace the current one(s).  
 If there are multiple consent and/or documents for this study, please indicate which consent and/or assent document(s) are to be replaced.
- B. Will enrolled subjects be informed of the change(s) described in this amendment?
- ☐ No. Please explain why not:  
☐ Yes. Will enrolled subjects be re-consented and/or re-assented?  
☐ Yes.  
☐ No. Please explain how enrolled subjects will be notified:
7. Amendment includes:
- |  |  |
|--|--|
| <input type="checkbox"/> Informed Consent and/or Assent, dated:                  | <input type="checkbox"/> Authorization, dated:     |
| <input checked="" type="checkbox"/> Summary Safeguard Statement, dated: 11-06-09 | <input type="checkbox"/> Protocol, dated:          |
| <input type="checkbox"/> Sponsor's Amendment, dated:                             | <input type="checkbox"/> Notice to Sponsor, dated: |
| <input type="checkbox"/> Clinical Investigator's Brochure, dated:                | <input type="checkbox"/> Advertisement, dated:     |
| <input type="checkbox"/> Other, dated:   |  |

NOTE: Only include documents that were checked in items 5 and 6 above (as being changed because of the amendment). Listing document dates are optional and only necessary if required by the investigator or sponsor.

**NOTE TO INVESTIGATORS:** Study amendments may not be instituted until approval from the IRB is given.

Please indicate the type of amendment you are submitting. See Guidelines for Determining an Amendment Type for additional information (<http://www.iupui.edu/~resgrad/spn/amend-guide.htm>). Please note that the IRB makes the final determination with regard to whether or not the amendment is acceptable for expedited review or if it requires review at a convened IRB meeting.

- ☒ **Minor Amendment.** Change(s) do not significantly affect the safety of subjects and is acceptable for expedited review per 45 CFR 46.110(b)(2)/21 CFR 56.110(b)(2).
- ☐ **Major Amendment.** Changes potentially involve increased risks or discomforts or decrease potential benefit. The amendment requires review at a convened IRB meeting.

#### SECTION IV: IRB APPROVAL

This amendment, including documentation noted in item 7 above, has been reviewed and approved as meeting the criteria for IRB approval as outlined in 45 CFR 46.111(a) by the IUPUI/Clarian IRB. I agree with the investigator's assessment above regarding whether the amendment is a minor or major amendment, unless otherwise noted.

Authorized IRB Signature: \_\_\_\_\_ IRB Approval Date: 7/29/10

Recorded in the Minutes of 8-6-10

v05/01/09

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